

AMENDED IN ASSEMBLY FEBRUARY 16, 2010

CALIFORNIA LEGISLATURE—2009—10 REGULAR SESSION

Assembly Concurrent Resolution

No. 117

Introduced by Assembly Members Hill and Huffman

(Principal coauthors: Senators Corbett and Leno)

**(Coauthors: Assembly Members Ammiano, Anderson, Block,
Caballero, Coto, Fletcher, Fong, Galgiani, Harkey, Hayashi,
Audra Strickland, Swanson, Torlakson, and Villines)**

(Coauthor: Senator Wyland)

February 4, 2010

Assembly Concurrent Resolution No. 117—Relative to Rare Disease Day.

LEGISLATIVE COUNSEL'S DIGEST

ACR 117, as amended, Hill. Rare Disease Day.

This measure would proclaim February 28, 2010, as Rare Disease Day.

Fiscal committee: no.

- 1 WHEREAS, There are nearly 7,000 diseases and conditions
- 2 considered rare (each affecting fewer than 200,000 Americans);
- 3 and
- 4 WHEREAS, While each of these diseases may affect small
- 5 numbers of people, rare diseases as a group affect almost 30 million
- 6 Americans; and
- 7 WHEREAS, Many rare diseases are serious and debilitating
- 8 conditions that have a significant impact on the lives of those
- 9 affected; and

1 WHEREAS, While approximately ~~340~~ 360 orphan drugs and
2 biologics have been approved for the treatment of rare diseases
3 affecting between 11 and 14 million people according to the United
4 States Food and Drug Administration, that leaves well over 15
5 million Americans affected by rare diseases with no treatment
6 specific to their disease; and

7 WHEREAS, Individuals and families affected by rare diseases
8 often experience problems such as a sense of isolation, difficulty
9 in obtaining an accurate and timely diagnosis, few treatment
10 options, and problems related to accessing or being reimbursed
11 for treatment; and

12 WHEREAS, Some rare diseases, such as Lou Gehrig's disease
13 and Huntington's disease, are relatively well known, many others
14 are not known at all by the public, making patients and their
15 families bear a large share of the burden for fundraising and
16 research; and

17 WHEREAS, Because one in 10 Americans have a rare disease,
18 ~~1,000~~ millions of residents of California are among those affected
19 by those diseases; and

20 WHEREAS, The National Organization for Rare Disorders
21 (NORD) is organizing a nationwide observance of Rare Disease
22 Day on February 28, 2010, on which patients, medical
23 professionals, researchers, government officials, and companies
24 developing treatments for rare diseases will join together to focus
25 attention on rare diseases as a public health issue; now, therefore,
26 be it

27 *Resolved by the Assembly of the State of California, the Senate*
28 *thereof concurring*, That the Legislature proclaims February 28,
29 2010, as Rare Disease Day in California; and be it further

30 *Resolved*, That the Chief Clerk of the Assembly transmit copies
31 of this resolution to the author for appropriate distribution.